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13. ABSTRACT (Maximum 200 Words) The <u>purpose</u> of this project is to develop and evaluate an Internet-based psychosocial intervention for women with primary breast cancer. During this funding period (10/1/99 to 9/31/00), the following <u>tasks</u> were completed: (1) a face-to-face psychosocial group for women with breast cancer was translated to an Internet-based program (with versions for WebTV, PC and Macintosh), (2) a format was developed to allow for the input of subjective states, (3) the initial program was reviewed by a group of women with breast cancer and changed as appropriate, and (4) nine women with primary breast cancer then participated in a 12-week, moderated program. <u>Results:</u> the pilot participants were extremely positive about the program. <u>Significance:</u> Women with primary breast cancer value participation in an on-line breast cancer psychosocial support group. The next phase of the project will involve a small outcome study to determine the effects of the program on 100 women with primary breast cancer randomized to usual care (wait-list control group) or the Internet intervention.				
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The Development and Evaluation of an Innovative Internet-Based Breast Cancer Psychosocial Intervention

DAMD17-99-1-9387 – 10/01/99-09/30/00

Principal Investigator: C. Barr Taylor, M.D.

INTRODUCTION

Breast cancer is the second leading cause of cancer death in women, exceeded only by lung cancer, and the leading cause of cancer death among women aged 40 to 55. The diagnosis of cancer is a universally upsetting event and a patient's response to this distress affects quality of life and treatment. While it has been found that social support may ward off or lessen emotional distress, women with breast cancer, because of their illness, treatment regimen and diminished social contact, frequently lose their social support. Psychosocial interventions have proved beneficial to improve quality of life and coping responses and to reduce psychological symptoms and pain in breast cancer patients. However, psychosocial interventions are often unavailable to cancer patients, particularly those living in rural areas or with transportation difficulties, too many competing responsibilities or other problems that would keep them from attending a group. The goals of this project are (1) to develop a comprehensive Internet-based psychosocial intervention for breast cancer patients, (2) to evaluate the feasibility, ease of use and perceived helpfulness of the new intervention with a group of women with breast cancer, and (3) to determine the effectiveness of this new approach with a small-scale, controlled pilot study. This program is an innovative approach to providing psychosocial interventions via the Internet. It employs 3 novel approaches to Internet-delivered programs: (1) structured, guided assignments rather than simply providing information, (2) a moderated support group rather than traditional unmoderated forums, and (3) employment of email and telephone reminders to enhance program adherence. If effective, this approach has the potential to help improve the quality of life for women with breast cancer. It will provide a cost-effective intervention which may help reduce patients' psychological symptoms, improve their coping skills, and may improve their adherence to medical regimens.

BODY

During this funding period (10/1/99 to 9/31/00), the following tasks were to be completed:

Task 1. To develop the Breast Cancer Psychosocial Support Group software including the user interface, content, and media (audio, graphics, and video) components (months 1-6).

- (a) Develop the structure of the intervention including the translation of the face-to-face group intervention to an electronic format.

As a first step, topics, issues, graphics and other material from the emotional-expressive groups and workbooks, which were the sources for our on-line group, were presented to a formative evaluation group of breast

cancer survivors. Formative evaluation group members reviewed content, recommended changes, and wrote and recorded personal recollections on these topics. The initial program was developed for the personal computer (PC and Macintosh) and tested with the same formative group. A second revision of the software was developed for a WebTV format. Both versions were then put onto a dedicated UNIX server.

- (b) Coordinate the efforts of the content developers and programming team (note that significant underlying software algorithms have already been developed).
This was accomplished on time.

- (c) Develop audio, video and graphic components.
This was accomplished on time. (Audio components were also transcribed to give users the material in written form if they preferred.)

- (d) Develop graphic representations of emotional states for group members to use in their computer-mediated discussions.

Formative evaluation group members could not agree on a graphic representation of emotional states. In our efforts to be inclusive, we decided to use text descriptors of emotional states. We initially developed a “pop-up” list of emotions, but the pilot participants insisted on free choice of descriptors.

- (e) Develop graphic representations of patient self-assessments (e.g., anxiety levels) for patient self-monitoring.
See (d) above.

- (f) Identify, select and meet with breast cancer patients who will participate in a formative group to provide feedback on audiovisual material, content, models, etc.

The group was formed 11/99 and met at least 6 times. The project director has had frequent contact with 2 of the members who have reviewed content and new designs.

- (g) Recruit 10-20 breast cancer patients for Phase 2.

Nine women were recruited for the Phase 2 trial. Because of the intensive feedback from the pilot group, we decided to limit the Phase 2 trials to this number.

Task 2. Pilot group/alpha field test software with a group of 10-20 breast cancer patients (months 7-12).

- (a) Train group moderator on computer-mediated group facilitation skills.

Done. The entire investigator team met weekly during the 12-week pilot group to review each week’s session and to discuss how moderation should occur.

- (b) Evaluate ease of use, comprehensibility of software, attractiveness of interface (graphics), and perceived benefit of the software.

Done. We solicited feedback from participants on the design, content and interface at the mid-point and end of the trial. In general, participants were extremely positive about the program. However, they didn't or couldn't access the audio. For this trial, we have transcribed all the audio. Verbatim comments from the last group are included in Appendix II.

- (c) Revise software based on feedback by subjects in the pilot study, advances in software/hardware technology and changes in medical knowledge.

The major changes based on feedback from the pilot group were: (1) the audio was transcribed so that it could be read, (2) assessments were placed online to reduce participant burden, (3) the frequency and specificity of moderator feedback was increased. However, as noted above, pilot subjects were very happy with the structure of the program.

Advances in software/hardware led to moving from a text-based database to an sql database, which permits much greater ease of data handling.

The following tasks are scheduled for years 2 and 3 of the project:

Task 3 Small group outcome study (months 13-30).

- (a) Recruit 100 women with primary breast cancer to the study.
(We have already recruited 40 women for the next phase of the study.)
- (b) Randomize women to usual care (wait-list control group) or psychosocial support group (intervention group). Five groups of 8-12 subjects each will be facilitated.
- (c) Complete pre- and post-test assessments of subjects.
- (d) Provide group intervention to wait-list control group subjects.

Task 4 Data analysis and report-writing (months 31-36).

- (a) Enter data.
- (b) Perform analysis of data obtained from subjects.
- (c) Prepare reports and initial manuscripts.
- (d) Evaluate software and make recommendations for future modification of software and intervention protocols.

Changes from original Statement of Work: None.

KEY RESEARCH ACCOMPLISHMENTS:

- Creation of a Web-based program to provide psychosocial support to women with primary breast cancer.
- Creation of a method to include “emotional” factors in on-line groups.
- A substudy comparison of group process (as coded by clinicians) with automated text analysis (see abstract in Appendix I).

REPORTABLE OUTCOMES

Alpers, GW, Winzelberg, AJ, Classen C, Dev P, Koopman C, Taylor CB.
Discourse analysis of a structured breast cancer support group. Society of Behavioral Medicine 22nd Annual Meeting, Seattle, WA, March 2001, submitted. (See abstract in Appendix I.)

CONCLUSIONS

An on-line Web-based program to provide psychosocial support to women with primary breast cancer has great potential. There was an extremely positive response to this program from the women in the pilot project. The next step is to determine its effectiveness/feasibility in a larger, controlled study that will be conducted over the next two years of funding.

REFERENCES

None.

APPENDIX I

DISCOURSE ANALYSIS OF A STRUCTURED BREAST CANCER SUPPORT GROUP

Georg W. Alpers, Dipl.-Psych., Andrew J. Winzelberg, Ph.D., Catherine Classen, Ph.D., Parvati Dev, Ph.D., Cheryl Koopman, Ph.D., and C. Barr Taylor, M.D.
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Participation in support groups has been found to be beneficial for women with breast cancer. Thousands of support groups are offered on the Internet but there is little research examining if and how they work. This study evaluates the discourse of an on-line breast cancer support group. The group was an 12-week semi-structured and moderated program. Each week group members were presented with content germane to the topic and designed to trigger the discussion. The 9 participants who had been diagnosed with primary breast cancer (mean age 53.1) and the moderator posted a total of 521 messages during the intervention. Participants logged on to read or write throughout the week and at all times of day. Individual patients posted an average of 4.6 (range 2.4-7.9) messages per week averaging 126 words per message (range 1-915). To increase the efficiency and accuracy of content analysis, we used Pennebaker and Francis' (1999) software, which maps relevant psychological dimensions. Their dictionary captured 83% of the words in the messages. The discourse pattern was stable throughout the intervention. A high percentage of words referred to positive concepts (5.6%) and fewer to negative concepts (1.7%). Social issues was the category most frequently used (10.7%). Moreover, post-intervention evaluations indicate that participants felt supported and trusted each other. Participants reported appreciating the 24-hour accessibility of the group, and they participated at times when traditional face-to-face groups are not available. Future studies should examine if the discourse pattern can predict treatment outcome of online groups.

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(299/300)

Appendix II

At the end of the 12-week program, subjects were asked what they liked about the program. Here is a summary of their responses:

"I share your lament that we do not meet face to face, cannot laugh together, cry together, hear each other's voices, see each other's expressions, and share hugs as we share pain and growth. But, on the other hand, I don't know that I'd have said as much or revealed as much of myself had we not had the shield of this impersonal medium. All the best, H"

"I have enjoyed the anonymity of the group. It is easier for me to air the feelings when I'm not looking at someone. Another person's expressions & body language may sway me from saying what I really wanted to get across. I have heard from the others their current struggles & have thought about them much more than I wrote. I'd log on to see how my buddies are doing, then be unprepared to put my thoughts down because of the sadness I felt, the desolation I felt, the helplessness I felt for that person (s). As my BC was in such early stage at diagnosis, I never underwent further treatment, & felt uncomfortable adding my 2 cents worth when I hadn't been there, done that. I have, however, read every word you all wrote & absorbed it like a sponge."

"I have gotten a lot out of being in this group; I am glad I had the chance to participate. I liked being able to log in when I had the energy/time, and not have to go out to a meeting some where. I feel that sharing other's personal experiences with their cancer helped put mine in perspective. I really appreciated that some Buddies were well past my stage (recently diagnosed), and that some were right where I am. I truly feel like I have had 'sisters' to guide me and offer words of encouragement when I really needed to hear them. Interestingly, I found I could 'relate' a little better to Buddies with pictures. maybe the image helps make the person more real.I have gained something from each person in the group. I would like to hear from anyone who wants to e-mail me: I'll keep logging on here for a while too! Especially I'll miss Catherine and our 'topics'! Even when we took off on different tangents."

"Saying good-bye is so much easier because we haven't formally seen each other in the flesh. That makes it easier for me as I am so swayed by body language & making the right impression, i.e. not too shy, too quiet, unparticipating, etc. So online has been good therapy for me. I have read everyone's entries with such gusto. I know you are all dealing with treatment & I can't relate to it. I can relate to the feelings of the diagnosis & I appreciate the frankness with which those who felt like saying WHY ME? said so. This is no time to be cavalier & assume the best. The best doesn't always come our way. Just by being diagnosed we all know that. The camaraderie of the group is what I enjoyed. No one was the prima donna with all the answers. We all tried to be supportive & not downplay the concerns & worries of others. Saying I felt like crying or felt angry or felt resentment was

honest & I felt you all listened. I'm not sure I can put my thoughts onto anything that I gained from the experience other than that I know I am not alone in my thoughts of this disease & just because I look fine I may not necessarily feel fine & that I need to convey those messages. Osmosis does not work here. S helped me realize I'm on the right path with my "assertiveness". I didn't know what to expect from this group. I signed up just because I fit the category & am desperately trying to reinforce in myself that I'm not alone in this diagnosis & its ramifications (fear, resentment, sadness, etc.)."

"Hi! I don't like to hear about "last messages"! You can all tell that I am a real chicken about good-byes since I have taken so long to try to say what I feel about our group. I think some of the others said things so well about how each of you have affected all of the others. I came to feel that I really knew some of you well and others sort of held back. I think Stevie said that she related more to the ones with pictures & I think that I did too. I think we are all so used to placing so much of our impressions of people on the physical aspect that it is hard to really identify with someone that we have not seen. But, it has been a good experience too to be able to share & not really know what some one looks like - to just focus on feelings. I think that the group has worked well being sort of anonymous. I think that I have been able to talk about some things that I have not been able to bring up when face to face in other groups - sexuality for instance - and some other private feelings. Since a small child I've always wanted everyone to like me & think that I am wonderful so have probably held back sometimes to not disillusion someone or put an added burden on them because of my emotions or physical condition. So, I will miss this outlet. In a way, I am sort of relieved to not have the commitment to the group. I've found myself spreading myself a little too thin with keeping up with the members of the group that I facilitate with every week. I find it emotionally draining to lead this group and have become so emotionally involved with members that it is hard on me emotionally. But, I am going to miss logging on & hearing of your joys and triumphs as well as aching for you in the bad times. I logged on several times over the weekend & saw no new messages & thought "Where is everyone?" I felt a loss not knowing what everyone was doing over the Father's Day weekend.

Since I was apparently the one in the group that was the farthest away from diagnosis & the most "experienced" I sort of relived all the traumas of treatments through those of you that are currently going through all the physical and emotional trials of diagnosis, surgery and treatment and all the affects that they have on everyday life and families. Persons who have never had a life threatening illness or who have been basically healthy all their lives are so fortunate but it is hard for them to relate to those of us who have been in the true "valleys". I hope that I've been able to share some information and support that helped some one a little.

I have admired you all so much for taking charge of your lives and enduring all the pain, trauma and worry with such good humor and perseverance. You are great gals!

Thank you Catherine and Andy. I know that this has been a lot of work for you. I appreciate your caring, Catherine, and the questions that you asked to lead our thinking and responses. It has been really helpful to me in thinking about ways to lead the other group. I would really like to be a "little mousie" in your office to learn

how you evaluate what we have done in this group. I would love to keep in touch with anyone who wants to."

"I feel a lot like I did when I went to summer camp. I didn't really know everyone very well, but by the end of four weeks, I didn't want it to end. I haven't been part of any other support group. It seemed like such a bother, having to go somewhere the same time each week, but this was so much better. We could sign on and see how everyone was doing. We could contribute a story or just read. Catherine's topics kept us focused on our development. I think that without a skilled moderator an on-line group could deteriorate into a bitch and gripe session. I'm not sure who it was, but someone belongs to other message boards and wished for someone like Catherine to moderate. I'm sure I would have contributed much less without her weekly topics. I know that for the past four weeks I haven't been very active due to my husband's problems. I also often felt that what I was going through re: breast cancer was trivial compared to what some of my buddies had to endure. I have learned a lot about survival, and more. About joy and courage and guts. I really appreciate the opportunity I have had to meet all of you, and I also don't want it to end."